

# Health Care Ethics USA

A quarterly resource for the Catholic health ministry

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# Transgender Persons and Catholic Healthcare

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*There is no Jew or Greek, servant or free, male or female; for you are all one in Jesus Christ.  
Galatians 3:28*

According to one study, the prevalence of gender identity disorder in the United States is between 4 and 5 per one hundred thousand persons.<sup>1</sup> This may be a small proportion, but according to an American Hospital Survey in 2013, Catholic health care services across the United States see more than 5.2 million persons per year. This means that those hospitals may care for more than 200 transpersons per year. Some questions arise: How should we treat persons who come to us as patients, whose driver's license still says "John Smith" but who presents herself, in dress and by name, as "Joan"? How about a surgeon, who wishes to perform gender-changing surgery on a patient as part of that person's transition from his or her natal sex to the other? Finally, is there anything within the wisdom of Catholic teaching that can guide us?

The purpose of this article is to outline in broad terms some of the fundamental issues for Catholic health care in the treatment of transgender persons. In order to do that, we first need to understand as much as possible about the actual condition of those persons, and also understand the potential biases we might bring to the discussion. The social landscape of discussions about sexuality has not always been a smooth one in the Catholic Church. At the same time, our profound respect for human dignity and our

enthusiastic embrace of all kinds of diversity give us taproots from which to grow.

Before we examine the contours of the issues facing Catholic health care, it is important to establish some common understanding of those assumptions that form the backdrop for further discussion. First, we must get our descriptions, definitions and terminology clear, including the meaning of sex and gender and the relationship between them. We should remind ourselves of how much we know, or do not, about human sexual development, including the many varieties and manifestations of difference. Finally, we will review a tool of moral reasoning, sometimes called the rule or principle of double effect, which can be helpful in thinking through a response.

## Descriptions and Definitions

First, although delicate sensibilities often lead people to say "gender" when they are actually referring to sex, there is a difference. Both terms can refer to the male/female division of the human species, but "sex" refers to the reproductive aspects of that difference, while "gender" refers especially to the social or behavioral aspects of it. The opposite of "euphoria," dysphoria means uncomfortable, hopeless or unhappy, a state of unease or generalized dissatisfaction with life. Gender dysphoria is the condition of being uneasy, uncomfortable or unhappy

because of one's gender.<sup>2</sup> Gender dysphoria is the sense of a transgender person that he or she was born into the body of the wrong sex.

Discussion of transgender issues and gender dysphoria in general can be confused by a misunderstanding of the appropriate terminology and what that terminology represents. The words *heterosexual*, *homosexual* and *bisexual* describe sexual attraction, grounded in biology but affected by culture.

Attraction can be fluid and changing, particularly in a culture that privileges heterosexual attraction as "normal" and homosexual or bisexual attraction as abnormal. Statistically, it is true that heterosexual attraction is most common—the propagation of the species depends on it. But whether homosexual or bisexual attraction is simply less usual, like people with red hair, or is considered sinful or sick depends on other assumptions, which are determined by culture and other philosophical commitments.

Medically speaking, these less common manifestations of sexual attraction are not considered disorders.

Gender identity, however, is independent of sexual attraction. Some persons who are born female but who feel male are attracted to women, some to men. Some persons who are born male but who feel female are attracted to men, some to women. Catholic teaching on the morality or immorality of homosexual activity is another issue and is not pertinent to moral questions regarding transgender persons.

Some gender dysphoric persons pursue medical treatment in order to transition to the opposite gender from the one they were born into. Treatment consists of counseling, then dressing and living as the other sex, along with hormone therapy affecting secondary sex characteristics. The next step in a transition is "top surgery," i.e., mastectomy for female-to-male (FtM) transpersons or breast augmentation for male to female (MtF) transpersons. The final step is "bottom surgery," which consists of refashioning the

urinary and reproductive structures into those of the new sex. Some transitions are complete without surgery, which is expensive and irreversible.

### What We Don't Know

Unlike the categories of sexual attraction, lack of concordance between one's physical sexual characteristics and one's gender identity is considered a pathology, although too little is known about how biology intersects with environment to understand it as thoroughly as we do, say, diabetes or cancer. The first and foremost aspect of gender dysphoria that is not well understood is the condition itself. What does it mean to "feel" male or female, apart from one's social conditioning? If gender is at least partly constructed, what part of it is given or innate? Researchers have begun to study the genetics of transgender persons,<sup>3</sup> which show differences from other men and women. There is also mounting physical evidence that gender identity is constructed by an interaction between hormones and the developing brain,<sup>4</sup> and there are structural differences in transgender persons' brains that make them look more like the brains of their desired sex than like those of other people in their natal sex.<sup>5</sup> Genetic, hormonal and structural evidence, then, seem to suggest that this psychiatric diagnosis has a biological substrate, not chosen and not socially constructed. Even with the explosion of technology for understanding the genetics and neuroscience of human biology, there is a great deal we do not understand. The relationship between gender and sex, and how the mind and the body connect them, is one example.

Certain aspects of human development are another example. We do know that in the progression from an embryo to a fetus to a born baby to a grown man or woman, there are stages of differentiation into male and female. The first stratum is the genetic

disposition. Most women have two X chromosomes and most men have an X and a Y. But some of us don't fall into those categories. There are individuals with XXY chromosomes and those with XYY or even XYYY. There are mosaic distributions of chromosomes that endow intersex individuals with both male and female characteristics. We do not fully understand how these non-typical chromosomes appear or why.

Persons with the typical XX or XY configuration go through one surge of feminizing or masculinizing hormones in utero and another one in adolescence. Some transgender theories posit that accidents in these surges can result in a person with the genetic endowment and physical characteristics of one sex but the internal disposition and feelings of the other. How these surges go wrong and how they change either brain structures or subsequent hormone releases are questions that are also poorly understood.

### Insights from Catholic Teaching

As anyone knows who has tried to research the teachings of the Catholic Church on the questions of transgenderism, these are questions on which the Church has not written directly or publicly. At the same time, there is much in scripture and in Catholic teaching about welcoming the stranger, about the respect for human persons, no matter who they are or what they look like, about the abundance of diversity in nature and the goodness of everything God creates. These alone are sufficient to understand the necessity of treating transpersons with respect. In any setting, including our hospitals and health services, that means using the pronoun and form of address the person prefers, respecting the person's presentation in the gender of choice, respecting the privacy of the person even if this is the first time we've known we are encountering someone who is different in this particular way.

But a hospital is also a special setting. In another service industry, we might respect a person's (chosen) social identity with comparative ease, by respecting form of address for example. In a hospital, however, caregivers see patients in varying states of vulnerability, including seeing their undressed bodies, and also have access to medical records containing facts that a patient would expect to be held in confidence. It is human to be curious and equally human to discuss curiosities with friends. In this case, the professional commitments of caregivers call them to rise above 'human nature,' and respect persons by not discussing them.

But what about surgery? Should a Catholic hospital perform top and bottom surgeries, to allow transgender persons to physically match their preferred sex? In the case of breast augmentation or mastectomy, we must think carefully before we deny such surgery. If we perform either of these surgeries for natal women who are dissatisfied with their natural endowment, or who have lost a breast due to pathology, we should probably allow it. Transpersons are persons who, it can be argued, are either missing normal breasts (MtF), or have them accidentally (FtM), due to a different kind of pathology. As we have seen above, evidence suggests changes in genetics, hormone delivery and brain structures are related to the incidence of gender dysphoria; it is not a choice.

Regarding bottom surgery, which can render a person sterile,<sup>6</sup> Catholic teaching gives us a long-used tool of moral analysis, i.e., the rule or principle of double effect. This tool allows us to think through whether a negative outcome is morally permissible when it is foreseen but not intended. The action undertaken must be good or at least neutral; the desired effect must be good; the bad effect must not be the means to the good effect and the action undertaken must be proportionate to the desired good outcome. A classic

example is in the case of a woman with uterine cancer who will die without a hysterectomy, but who is found to be pregnant before undergoing it. The loss of fetal life is a regretted, foreseen but undesired and unintended outcome. The rule of double effect justifies the hysterectomy and the loss of fetal life.

In the case of bottom surgery that will sterilize the person, I believe that we can use the rule of double effect in a similar way. The surgery itself is neutral. The good effect, from the perspective of the person undergoing it, is that his or her body will come to present to the world the person in the gender he or she experiences inside. The relief of suffering this represents is profound. The inability to bear or father a child is a regrettable and foreseen consequence, but it is not a means to the good end. Indeed, some transpersons desperately wish their reproductive function did not have to be sacrificed, and in fact some go through a transition in such a way as to preserve it. Sterilization, then, is a side effect of correcting what amounts to a birth defect. It is an unintended but foreseen consequence.

## Conclusion

In summary, gender dysphoria is a pathological condition in which the sex and gender of a person do not match. Science is beginning to understand the etiology of gender dysphoria, but it is still in the early stages of knowledge. Due to advances in endocrinology, plastic surgery and urology, this condition is sometimes treated with hormones and surgery. The result of these can be to render a person sterile, but this is a side effect of treating an all-pervasive birth defect, not an intentional contraceptive sterilization.

Because this condition is relatively rare, and also because it affects socially freighted aspects of our humanity—sex and gender—many in Catholic health care are unfamiliar with it. That should not prevent

us from rendering compassionate care. Furthermore, Catholic health care institutions should be cautious about developing practices that could violate their own policies of non-discrimination, particularly in light of the federal government's recognition of transgender individuals as members of a protected class.<sup>7</sup>

**What do you think?** If you'd like to comment on this article please email your thoughts to [HCEUSAeditor@chausa.org](mailto:HCEUSAeditor@chausa.org). We'll collate responses for the next issue.

<sup>1</sup>: John R. Blosnich, George R. Brown, Jillian C. Shipherd, PhD, Michael Kauth, Rebecca I. Piegari, and Robert M. Bossarte. "Prevalence of Gender Identity Disorder and Suicide Risk Among Transgender Veterans Utilizing Veterans Health Administration Care." *American Journal of Public Health*: October 2013, Vol. 103, No. 10, pp. e27-e32

<sup>2</sup> In 2013, the Diagnostic and Statistical Manual, published by the American Psychiatric Association, updated its entry from "gender identity disorder" to "gender dysphoria." Its inclusion in the manual reflects the way it is treated and the way that treatment gets paid for.

<sup>3</sup> Hare, L; Bernard, P; Sanchez, F; Baird, P; Vilain, E; Kennedy, T; Harley, V (2009). "[Androgen Receptor Repeat Length Polymorphism Associated with Male-to-Female Transsexualism](#)". *Biological Psychiatry* **65** (1): 93–6 (2009); Bentz, E; Hefler, L; Kaufmann, U; Huber, J; Kolbus, A; Tempfer, C (2008). "A polymorphism of the CYP17 gene related to sex steroid metabolism is associated with female-to-male but not male-to-female transsexualism". *Fertility and Sterility* **90** (1): 56–9 (2008).

<sup>4</sup> "A Sex Difference in the Human Brain and its Relation to Transsexuality." J.-N. Zhou, M.A. Hofman, L.J.G. Gooren and D.F. Swaab. *Nature*, 378: 68-70 (1995).

<sup>5</sup> Chung, WC; De Vries, GJ; Swaab, DF. "Sexual Differentiation of the Bed Nucleus of the Stria Terminalis in Humans May Extend Into Adulthood". *The Journal of Neuroscience* **22** (3): 1027–33.(2002); Garcia-Falgueras, A.; Swaab, D. F. "A Sex Difference in the Hypothalamic Uncinate Nucleus: Relationship to Gender Identity". *Brain*

131 (Pt 12): 3132–46.(2008); Luders, Eileen; Sánchez, Francisco J.; Gaser, Christian; Toga, Arthur W.; Narr, Katherine L.; Hamilton, Liberty S.; Vilain, Eric "[Regional gray matter variation in male-to-female transsexualism](#)". *NeuroImage* 46 (4): 904–7(2009).

<sup>6</sup> but doesn't always. Some FtM transpersons keep ovaries and uterus, allowing them to become pregnant.

<sup>7</sup><http://www.washingtonblade.com/content/files/2015/03/259302140-0-14-cv-02037-31.pdf>

# Sex Reassignment Surgery and the Catholic Moral Tradition: Insight from Pope Pius XII on the Principle of Totality

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A common argument among Catholic theologians and ethicists against sex reassignment surgery (SRS) is that it either violates the principle of totality or constitutes a direct sterilization. These procedures generally fall into one of three categories: breast (augmentation mammoplasty, subcutaneous mastectomy), genital (vaginectomy, hysterectomy, scrotoplasty, phalloplasty, penectomy, castration, vaginoplasty, etc.), and nongenital/nonbreast (liposuction, lipofilling, lowering or raising the voice pitch, chondroplasty, hair reconstruction, etc.).<sup>1</sup> Some of these procedures are also done outside the context of SRS for cosmetic reasons and others for therapeutic purposes.<sup>2</sup> These can certainly be considered morally licit in that context.

Within the context of SRS, however, many arguments hold that procedures related to SRS are unjustified because the excised tissues and organs are healthy and the principle of totality only allows for the destruction or removal of body parts that are diseased or pathological.<sup>3</sup> After all, the threat that the pathology poses to the health or life of the body as a whole is what justifies the violation of bodily integrity, and without a pathology there is no threat. With regard to genital procedures, without an underlying pathology,

any removal or restructuring of genital organs involved in SRS would likely constitute a direct sterilization, which is always unjustified. Thus, so the argument goes, SRS is morally impermissible.

However, several authors (myself included) have noted that Pope Pius XII taught that it is not necessary for a body part to be pathological in order to justify its removal or alteration.<sup>4</sup> He gives three criteria for justifying any procedure that results in anatomic or functional mutilation:

1. The retention or function of a particular organ within the whole organism is causing serious damage or constitutes a threat to it;
2. The damage or threat cannot be avoided, or even notably diminished, except by a mutilation in question and whose efficacy is well-assured; and
3. It is reasonable to expect that the negative effect will be compensated for by the positive effect.<sup>5</sup>

Yet Pius XII recognizes that in some cases, a healthy organ's normal, natural functioning might threaten

the health or life of the whole body. He says that “the decisive point here is not that the organ which is amputated or rendered incapable of functioning be itself diseased, but that its retention or functioning either directly or indirectly brings about a serious threat to the whole body.”<sup>6</sup> He illustrates this with the example of a bilateral orchiectomy (removal of both testicles) in a patient with prostate cancer; the testicles produce hormones that can increase the cancer’s spread.<sup>7</sup> Thus, according to Pius XII, the principle of totality in fact *does not* require a body part to be diseased or pathological to justify its amputation, removal, suppression, or destruction if its normal functioning exacerbates a pathology in another part of the body.

Furthermore, Pius XII’s example shows that this is even true when the healthy body part is a reproductive organ. If it results in sterilization, this could be justified as an indirect, unintended, but foreseen side effect that is justified by the positive effect of treating, eliminating, or diminishing the pathology elsewhere in the body. Unlike a tubal ligation to prevent problems with a future pregnancy, sterility does not prevent the spread of prostate cancer but the accompanying lack of hormones does.

Given these points, it appears that SRS could be justified from a Catholic moral perspective. For the first criterion, the continued presence and normal functioning of the various body parts involved contributes to and exacerbates another illness, namely gender identity disorder, which was recently renamed gender dysphoria. For the first part of the second criterion, patients typically undergo months if not years of counseling and hormone therapy before turning to SRS as a last resort.<sup>8</sup> These less-invasive interventions would have to be required in order for SRS to meet this criterion. However, it is not clear if SRS meets the last part of the second criterion or any of the third.

The second half of the second criterion relates to the efficacy of the proposed procedure. Unfortunately, it is still unclear if SRS is effective at relieving the distress of gender dysphoria. Several studies report that people who undergo SRS are largely satisfied with the results, while only about 1-3% experience serious regret.<sup>9</sup> Yet, most of these studies are known to be of poor quality.<sup>10</sup> More importantly, self-reported satisfaction does not appear to be a sufficient measure for success, especially since many of those who undergo SRS continue to have related mental health problems.<sup>11</sup> At the very least, the evidence cannot support the claim that “the efficacy of SRS is well-assured” to relieve the mental health concerns associated with gender dysphoria.

Pius XII’s third criterion is a compensation of bad effects by good effects, which I read as a description of proportionate reasoning. Even if further research shows that SRS is an effective long-term treatment for gender dysphoria, it is not at all clear that SRS compensates for the negative effects of sterilization and mutilation. For example, Pius XII’s example of orchiectomy in prostate cancer is an effective treatment, but the positive effect is quite significant; it extends the patient’s lifespan which could allow direct treatment of the cancer to eliminate the disease altogether. With SRS, the patient’s life is not at stake; the positive effect improves the quality of life but does not save or extend life. Yet, Pius XII states the principle of totality allows a patient to destroy body parts “to ensure his existence, or to avoid, and, naturally, to repair grave and lasting damage, that could not otherwise be prevented or repaired.”<sup>12</sup> The greater the alteration, the graver the condition needed to justify it.<sup>13</sup> This does not necessarily mean that every alteration must prevent or diminish a fatal illness, but one as substantial and invasive as SRS likely should. If the illness is not fatal, like gender dysphoria is not, then the condition must be grave (which gender dysphoria certainly can be), all other



measures must have been tried and failed, and the intervention must be known to have high efficacy.<sup>14</sup> As stated before, SRS does not meet this last requirement.

However, another comment from Pius XII reveals a possible avenue for morally justifying SRS. Conceptually, the principle of totality stems from the metaphysical understanding of the part-whole relationship; a part exists for the sake of the whole, thus removing the part can be justified if it benefits the whole. When applying the principle of totality to medical interventions, “whole” is typically understood to mean the patient’s body.<sup>15</sup> Yet, Pius XII states that a patient “may use individual parts, destroy them or mutilate them, when and to the extent necessary for the good of his being as a whole.”<sup>16</sup> The phrase “being as a whole” implies more than just a benefit to the physical body. It acknowledges our obligation to care for the whole person, and that health care should embrace “the physical, psychological, social, and spiritual dimensions of the human person” because Jesus sought ‘physical, mental, and spiritual healing.’<sup>17</sup>

If Pius XII’s phrase “being as a whole” is interpreted as the whole person, it sheds new light on the principle of totality than the typical understanding that deals only with benefit to the physical body. This is especially interesting if gender dysphoria is understood as a disconnect between the soul and the body, i.e. an inability of the form to properly manifest itself due to a defect in the matter.<sup>18</sup> That being said, much study remains to be done on the causes of gender dysphoria and the efficacy of SRS at relieving the symptoms before such a justification could occur.<sup>19</sup>

This conclusion might concern some because it does not reject SRS necessarily, as an inherently

unjustified mutilation or direct sterilization, and instead rejects it conditionally, i.e., only if empirical evidence shows that the burdens outweigh the benefits.

For example, one could argue that the different intention between a woman requesting an augmentation mammoplasty for cosmetic purposes and a man requesting it as part of SRS means the two procedures necessarily have different objects. This would allow for a different moral evaluation of each one, and could justify permitting it for cosmetic purposes in women but prohibiting it for SRS in men. While this might be sufficient to avoid accusations of discrimination and cisgenderism, exploring this question is beyond the scope of this paper. However, I see this conclusion as one that recognizes the limits of human knowledge and is open to the possibility of error. Just as ethics must be based on metaphysics, so too bioethics must be based (in part) on empirically verified facts. Unfortunately, despite numerous theories regarding the origin of gender dysphoria, its cause is still unclear, and good evidence on the effectiveness of SRS (measured by something other than patient satisfaction) is lacking.

Consequently, in my judgment, procedures required for SRS that are not morally justified could be justified depending on the outcome of further research.<sup>20</sup> Ultimately, if SRS procedures are determined to be morally justified, one must still ask whether this is an appropriate use of limited resources, especially given the many demands on the health care system and the amount of capital it would require to create a center large enough to provide SRS with sufficient standards of clinical quality and safety. In the meantime, we can at least be confident that Pope Pius XII’s insights on the principle of totality show that simply because SRS removes healthy, non-pathological body parts and results in sterility does not mean it is unjustified. These are morally relevant

but not morally determinative factors when assessing SRS.

**What do you think?** If you'd like to comment on this article please email your thoughts to [HCEUSAeditor@chausa.org](mailto:HCEUSAeditor@chausa.org). We'll collate responses for the next issue.

<sup>1</sup> R. Ettner, S. Monstrey, and A.E. Eyler, *Principles of Transgender Medicine and Surgery* (Taylor & Francis, 2013), 110, 36-37.

<sup>2</sup> For example, mastectomy and augmentation mammoplasty are regularly done for breast cancer patients, penectomy for penile cancer, phalloplasty after severe trauma to the groin, vulvoplasty after a vulvectomy for vulvar cancer, or chondroplasty for those who want to reduce the size of the Adam's apple.

<sup>3</sup> This is an admittedly cursory summary that does not do justice to the longer arguments presented by others: Richard P Fitzgibbons, Philip M. Sutton, and Dale O'Leary, "The Psychopathology of "Sex Reassignment" Surgery," *The National Catholic Bioethics Quarterly* 9, no. 1 (2009): 4; Orville N. GRIESE, *Catholic Identity in Health Care: Principles and Practice* (Pope John Center, 1987), 228-29; Benedict M. Guevin, "Sex Reassignment Surgery for Transsexuals: An Ethical Conundrum?," *The National Catholic Bioethics Quarterly* 5, no. 4 (2005): 719, 29-34; Tad Pacholczyk, "Changing My Body to "Match" My "Identity?,"" *Making Sense of Bioethics* (August 2015); Nicholas Tonti-Filippini, "Sex Reassignment and Catholic Schools," *The National Catholic Bioethics Quarterly* 12, no. 1 (2012): 93-94.

<sup>4</sup> Father Nicanor Austriaco et al., "Medical Intervention in Cases of Maternal-Fetal Vital Conflicts," *National Catholic Bioethics Quarterly* 14, no. 3 (2014); GRIESE, *Catholic Identity*, 217; Emily Trancik, Cherie Sammis, and Becket Gremmels, "Prophylactic Salpingectomy to Reduce the Risk of Cancer: Ethical Considerations," *Health Care Ethics USA* 23, no. 1 (2015); Germain Kopaczynski, "Selected Moral Principles: Totality and Integrity," in *Catholic Health Care Ethics: A Manual for Practitioners*, ed. Edward James Furton, Peter J. Cataldo, and Albert S. Moraczewski (National Catholic Bioethics Center, 2009).

<sup>5</sup> "le maintien ou le fonctionnement - d'un organe particulier dans l'ensemble de l'organisme provoque en celui-ci un dommage sérieux ou constitue une menace. Ensuite que ce dommage ne puisse être évité, ou du moins notablement diminué que par la mutilation en question et que l'efficacité de celle-ci soit bien assurée. Finalement, qu'on puisse raisonnablement escompter que l'effet négatif, c'est-à-dire la mutilation et ses conséquences, sera compensé par l'effet positif," Pope Pius XII, "Address to the Participants of the 26<sup>th</sup> Congress of the International Society of Urology," October 8, 1953. All English translations of Pius XII's allocutions in this article are my own, from the original French.

<sup>6</sup> "Le point décisif ici n'est pas que l'organe amputé ou rendu incapable de fonctionner soit malade lui-même, mais que son maintien ou son fonctionnement entraîne directement ou indirectement pour tout le corps une menace sérieuse." Pope Pius XII, "Address to the Congress of Urology," 1953.

<sup>7</sup> Pope Pius XII, "Address to the Congress of Urology," October 8, 1953. While a medical alternative is usually possible today, orchiectomy is still recommended in certain situations. Nima Sharifi, James L Gulley, and William L Dahut, "Androgen deprivation therapy for prostate cancer," *JAMA* 294, no. 2 (2005).

<sup>8</sup> William Byne et al., "Report of the American Psychiatric Association task force on treatment of gender identity disorder," *Archives of Sexual Behavior* 41, no. 4 (2012): 765.

<sup>9</sup> Jochen Hess et al., "Satisfaction With Male-to-Female Gender Reassignment Surgery: Results of a Retrospective Analysis," *Deutsches Ärzteblatt International* 111, no. 47 (2014); Byne et al., "Report of the American Psychiatric Association," 780-82.

<sup>10</sup> Girolamo Morelli et al., "Follow-Up of Patients After Male-to-Female (Mtf) Sex Reassignment Surgery (SRS)," in *Management of Gender Dysphoria*, ed. Carlo Trombetta, Giovanni Liguori, and Michele Bertolotto (Springer, 2015), 185; Mohammad Hassan Murad et al., "Hormonal therapy and sex reassignment: a systematic review and meta-analysis of quality of life and psychosocial outcomes," *Clinical Endocrinology* 72, no. 2 (2010).

<sup>11</sup> Cecilia Dhejne et al., "Long-Term Follow-Up of Transsexual Persons Undergoing Sex Reassignment Surgery: Cohort Study in Sweden," *PLoS One* 6, no. 2

(2011); Rikke Kildevæld Simonsen et al., "Long-term follow-up of individuals undergoing sex reassignment surgery: Psychiatric morbidity and mortality," *Nordic Journal of Psychiatry* (2015), Published electronically 10/19/2015.

<sup>12</sup> "pour assurer son existence, ou pour éviter, et, naturellement, pour réparer des dommages graves et durables, qui ne pourraient être autrement ni écartés ni réparés." Pope Pius XII, "Address to the Participants of the International Congress of Histopathology of the Nervous System," September 13, 1952.

<sup>13</sup> See: Griese, *Catholic Identity*, 217-18; Albert S. Moraczewski and John B. Shea, "Genetic Medicine," in *Catholic Health Care Ethics: A Manual for Practitioners*, ed. Edward James Furton, Peter J. Cataldo, and Albert S. Moraczewski (National Catholic Bioethics Center, 2009), 238-39. Regarding SRS specifically, see: Tonti-Filippini, "Changing My Body," 85; Benedict Ashley, Jean Deblois, and Kevin O'Rourke, *Health Care Ethics: A Catholic Theological Analysis*, 5th ed. (Washington, D.C.: Georgetown University Press, 2006), 111.

<sup>14</sup> Note that gender dysphoria is not always a grave condition as the majority of cases in children do not persist into adulthood. See Byne et al., "Report of the American Psychiatric Association," 763.

<sup>15</sup> Thomas Aquinas, *Summa theologiae*, II-II, q. 65, a. 1, corpus. Griese, *Catholic Identity*, 218, 385-86.

<sup>16</sup> "il peut disposer des parties individuelles pour les détruire ou les mutiler, lorsque et dans la mesure où c'est nécessaire pour le bien de l'être dans son ensemble," Pope Pius XII, "Address to the Congress of Histopathology," September 13, 1952.

<sup>17</sup> USCCB, *Ethical and Religious Directives for Catholic Health Care Services*, 5<sup>th</sup> edition, 2009, Introduction to Part Two.

<sup>18</sup> Peter Kreeft, *Everything You Ever Wanted to Know about Heaven: But Never Dreamed of Asking* (Ignatius Press, 1990), 123; Griese, *Catholic Identity*, 229-30.

<sup>19</sup> Even a cursory review of gender dysphoria itself and its origins are outside the scope of this article, as its focus is only on SRS and the principle of totality. Personally, I believe an amalgam of causes is at work, but I find the psychological origin theories to be particularly compelling. See Fitzgibbons, "Psychopathology." Theories of biological origin are also plausible. See Daniel Klink and

Martin Den Heijer, "Genetic Aspects of Gender Identity Development and Gender Dysphoria," in *Gender Dysphoria and Disorders of Sex Development*, ed. Baudewijntje P.C. Kreukels, Thomas D. Steensma, and Annelou L.C. de Vries (Springer, 2014).

<sup>20</sup> For similar positions see Griese, *Catholic Identity*, 230; William May, "Sex Reassignment Surgery," *Ethics & Medics* 13, no. 11 (1988). For those who argue that SRS is unjustified regardless of its origin, see Christopher Gross, "Karol Wojtyła on Sex Reassignment Surgery," *The National Catholic Bioethics Quarterly* 9, no. 4 (2009): 720; Benedict M. Guevin, "Sex Reassignment Surgery for Transsexuals: An Ethical Conundrum?," *ibid.* 5 (2005): 732-33.

## Feeding Tubes in Advanced Dementia and Ischemic Stroke

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*Editor's Note: This is a written summary of a CHA webinar entitled "Medically Administered Nutrition and Hydration: Is It Ethically Required with Dementia and Stroke Patients?" delivered by Dr. Sheehan on November 3, 2015.*

In the Catholic tradition, when oral feeding and hydration are not possible, decisions to institute medically assisted nutrition and hydration (MANH) have a presumption in favor of such treatment. This presumption of use, however, depends on the clinical context and the judgement of the person being treated as to benefits and burdens of the treatment.

Although a presumption of treatment exists, considerations of efficacy, safety, discomfort, and other burdens must be considered. Frequently, decisions about MANH are made regarding persons with advanced dementia or individuals who have suffered an ischemic stroke. (An ischemic stroke is a stroke caused by a loss of blood flow to the brain, usually because of a clot in an artery supplying the brain or an artery in the brain.) Attention to the clinical situation in both categories can be of assistance in making decisions about MANH.

In this article, the focus is on feeding tube use rather than intravenous assisted nutrition and hydration. This latter type of therapy is invasive, expensive, and can be lifesaving in certain situations but its use requires sophisticated medical monitoring and careful

attention to potential complications. Feeding tubes, whether nasogastric feeding tubes or PEG tubes (percutaneous endoscopic gastrostomy), are far more common. There is a growing consensus against the use of feeding tubes in advanced dementia because of a lack of efficacy in sustaining life in the face of an inexorably fatal illness. The situation with ischemic stroke is more complicated with feeding tube decisions depending on the age of the patient, previous functional status, amount of brain tissue injured by the stroke, and the patient's previously expressed wishes.

Treatment decisions depend on the risks and benefits of the treatment, technical aspects and efficacy, patient outcomes and ethical aspects surrounding the treatment. Nasogastric tubes are usually indicated for a short period of feeding, about six weeks, with complications arising from irritation of the nose, back of the throat, and esophagus occurring with longer term use. Many people, however, do have nasogastric tubes in place for a prolonged period of time. PEG tubes are more common and are placed with the assistance of an endoscope that is directed

through the mouth into the stomach and a tube is inserted through the abdominal wall into the stomach. Both types of tubes usually supply prepared formulas that can be given as a prolonged drip feeding or as a bolus feeding several times a day. There is a need to monitor fluid and electrolyte status and other metabolic parameters. Many patients, particularly with nasogastric tubes, need to be restrained to avoid deliberate or inadvertent removal of the tube. These types of tubes can move and may need to be repositioned, a procedure that usually involves a hospital trip for verification that the tube is in the stomach and has not migrated into the trachea or the lungs. PEG tube placement carries risks related to the surgical procedure, local irritation, and infection. Both types of tube feedings can be complicated by diarrhea. Even though most of the time, tube placement is relatively safe and complications can be managed, the possibility of complications – rarely, even death with PEG tubes -- is real. The need for ongoing restraints may be particularly distressing.

Directive #58 of the *Ethical and Religious Directives for Catholic Health Care Services* directly addresses the use of MANH and feeding tube use.

In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g. “the persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when there would “be excessively burdensome for

the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.” For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.<sup>1</sup>

There is a growing consensus that advanced dementia is a condition where the placement of a feeding tube is not morally required. In a 2009 article in the *New England Journal of Medicine*, the authors documented that swallowing difficulties, aspiration, pneumonia, and multiple other problems are common in patients with advanced dementia. Studying a group of these over eighteen months, greater than 85% had difficulties with eating and the subsequent six month mortality was near 50%.<sup>2</sup> Although feeding tubes have been advocated to prolong life, limit aspiration pneumonia, improve function and maintain comfort, studies do not document these assertions. In a 2014 position statement on feeding tubes in advanced dementia, the American Geriatric Society, making recommendations based on the latest literature, presented this position statement:

Feeding tubes are not recommended for older adults with advanced dementia. Careful hand feeding should be offered; for persons with advanced dementia, hand feeding is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status, and comfort. Tube feeding is associated

with agitation, greater use of physical and chemical restraints, greater healthcare use due to tube-related complications, and development of new pressure ulcers.<sup>3</sup>

With regard to ERD # 58, it seems clear that we should exercise great care before embarking on the placement of an NG tube, and even more so with the more invasive PEG tube. A program of careful hand feeding is more humane and appears to be just as effective. The moral nature of the use of feeding tubes in ischemic stroke is not as clear cut. Ischemic stroke has a variety of different outcomes. A small stroke in a relatively young and previously healthy person likely will have a good outcome, even if the location of the stroke necessitates at least a period of tube feeding until swallowing function is recovered. On the other hand, an older person who has had multiple health problems and who has a large stroke is likely to do poorly with or without a feeding tube. There are multiple clinical possibilities in between these two scenarios. The prognosis for survival after an acute ischemic stroke depends on the severity of the stroke, with severity measured either by the location of the stroke in an area that controls vital functions or by the sheer amount of brain affected.<sup>4</sup> In younger persons, the cause of an ischemic stroke is often different than in older persons and has a usually better prognosis.<sup>5</sup>

There is a lack of clear knowledge relating to the long term recovery of swallowing function in persons with ischemic stroke. This complicates decision making. One recent study notes

Up to 70% of acute stroke patients demonstrate dysphagia. Approximately half of these patients recover sufficient swallowing ability to meet their caloric needs, while the other half will have long-term

swallowing dysfunction. Surgical feeding tubes can provide nutritional support in patients with severe dysphagia, but the decision of if and when to place a feeding tube poses a substantial challenge because of an inability to predict long term recovery accurately.<sup>6</sup>

Factors that would recommend use of a feeding tube, either nasogastric tube or PEG, are those associated with improved survival: younger age, limited infarct, fewer clinical deficits. The burdens increase and the benefits become more questionable with tube placement in those who are older, had large strokes with massive clinical deficits, or had poor functional status prior to the stroke. Tube feeding is advisable in younger patients with a good prognosis but there is a need for more caution in older patients, especially those with previous difficulties.

In all these decisions, attention to the patient's perception of benefits and burdens is important. If the patient is unable to participate in decision making and did not give clear advance directives, the surrogate decision maker should make every attempt to see the situation from the patient's perspective. Clearly, there are many grey areas that require individual assessment, careful decision making, and prudent attention to patient wishes. However, in the case of an old person who has been previously healthy but has had a massive stroke, I do not believe there is an obligation to start tube feeding as the burdens are real and benefits at best unclear.

In summary, patients with feeding disorders and advanced dementia are dying regardless of feeding tube placement. Tube placement is associated with risks and few benefits. Health care facilities should not require or recommend tube placement in these cases and, instead, have programs for hand feeding and

education of family and staff as to prognosis. The situation in ischemic stroke is less clear cut and requires assessment on a case by case basis, considering the cause of the stroke, clinical deficits and size of stroke, patient's age and previous health, and patient wishes.

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<sup>1</sup> United States Conference of Catholic Bishops. *Ethical and Religious Directives for Catholic Health Care Services*, Fifth Edition. 2009. P. 41.

<sup>2</sup> Mitchell SL, Teno JM, Kiely DK et al. "The Clinical Course of Advanced Dementia." *New England Journal of Medicine* 2009; 361:1529-1538.

<sup>3</sup> American Geriatrics Society. American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement. *Journal of the American Geriatrics Society* 2014; 62:1590-1593.

<sup>4</sup> Edwardson MA, Dromerick AW. "Ischemic Stroke Prognosis in Adults." 2015. Up to Date. [www.uptodate.com](http://www.uptodate.com).

<sup>5</sup> Varona J. Long-term Prognosis of Ischemic Stroke in Young Adults. *Stroke Research and Treatment* 2011. Article ID 879817. doi:4061/2011/879817

<sup>6</sup> Willis AW, Williams L, Mullen MT. Feeding Tube Placement in Stroke Patients. *Neurology* 2014; 83:870-871.

Currents are unpredictable, and they can be dangerous, carrying us along to places we don't want to go. Yet currents also indicate the vitality of a lake or a sea.

I guess ethical currents are about the same thing. Sometimes, as with transgender issues, we are hit suddenly with things we don't expect. Caitlin Jenner's sudden and very public revelation of her gender status raised a lot of ethical issues in a short time. We've known about transsexuality for a long time (rabbinic scholars note several words for different genders even in the Middle Ages) but I think this time publicity got ahead of ethics and that is one of the reasons we have not given it the ethical analysis it deserves. Fortunately, we have excellent articles by **Becket Gremmels** of CHRISTUS Health and **Carol Bayley** of Dignity Health. You'll note that they reach somewhat different conclusions. I think that's pretty much the state of the question. As both of them note, there is much we don't yet know so we must be careful not to resolve the many issues too quickly. I hope their articles stimulate some healthy professional discussion among us. We plan to feature additional articles about this topic through the year. Please feel free to respond with questions or comments to [HCEUSAeditor@chausa.org](mailto:HCEUSAeditor@chausa.org) about these and other articles in HCEUSA. We look forward to your thoughts and suggestions for future topics!

We also have a summary of a recent CHA webinar in the "From the Field" section presented by **Fr. Myles Sheehan, S.J.**, on tube feeding for elderly patients and those suffering from dementia. He presents a fine overview of clinical experience and moral analysis.

Related to this is a review of several articles about geriatric dialysis, which our Mission Program and Research Association **Lori Ashmore-Ruppel** and I did. Most of the articles we reviewed suggested criteria for decision making, but several also noted

that education for physicians is an important need. Again, we hope this review will prompt some of you to share your own experience.

Last, **Nate Hibner** of the Saint Louis University Center for Health Care Ethics and students from the Saint Louis University School of Law under the direction of **Amy Sanders**, assistant director of the Center for Health Law Studies, have prepared a list of "Notable" items in the media for the Of Note section.

And finally, our graphic designer **Les Stock** has brightened up our masthead. We took this refresh as an opportunity to add "Quarterly" to the subtitle.



## The Myth Regarding the High Cost of End-of-Life Care

Authors Melissa Aldridge and Amy Kelley in an article in the *American Journal of Public Health* question the data set from which the current discussion on high-cost health care populations derive. They claim the “evidence is biased...in that most studies have examined only Medicare expenditures and, therefore, only the Medicare population.” The authors’ “estimates draw upon a combination of data from existing national data sets (including the Medical Expenditure Panel Survey [MEPS] and the Health and Retirement Study), the peer-reviewed literature, and published reports.” These sources estimate the total expenditure for health care in 2011 as \$1.6 billion. Of this, “13 percent, or \$205 billion, was devoted to care of individuals in their last year of life.” On further examination, the numbers reveal that from the individuals who make the top 5 percent of total annual health care spending, only 11 percent were in their final years. This leads the authors to discover the three “broad illness trajectories” which, when combined, make up the highest spending population:

- 1) individuals who have high health care costs because it is their last year of life (population at the end of life); 11 percent
- 2) individuals who experience a significant health event during a given year but who return to stable health (population with a discrete high-cost event); 49 percent
- 3) individuals who persistently generate high annual health care costs owing to chronic conditions, functional limitations, or other conditions but who are not in their last year of life and live for several years generating high health care expenses (population with persistent high costs); 40 percent.

Based on their findings, the authors conclude “the need to focus on those with chronic serious illnesses, functional debility, and persistently high costs” and that programs aimed at these subgroups will be better able to contain and reduce the highest cost population. Melissa Aldridge and Amy Kelley, “The Myth Regarding the High Cost of End-of-Life Care,” *American Journal of Public Health* 105:12, Dec. 2015. <http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2015.302889>

## 2016 Will Bring in a Flurry of New Rules and Regulations Affecting Healthcare

In the January 2016 edition of *Modern Healthcare*, the publication included a timeline for upcoming new rules and regulations for 2016. The list is broken down by month and contains over two dozen changes. These changes include:

- 1) This year, all employers with at least 50 full-time-equivalent employees must offer affordable health insurance or face penalties under the Affordable Care Act, which would be a minimum of \$2,000 per full-time employee. Previously, the rule applied only to companies with 100 or more FTE employees.
- 2) In March the Office for Human Research Protections at the U.S. Department of Health and Human Services and 15 other federal agencies will issue a final rule updating the “Common Rule” governing research on human subjects.
- 3) In mid- to late-2016, the FDA is expected to issue rules for electronic cigarettes that could require the agency to regulate e-cigarettes as drugs or devices.
- 4) In November the CMS will issue a rule requiring health care providers to develop discharge plans for all Medicare inpatients and certain outpatients.

A complete list of upcoming rules and regulations is contained in the article. “2016 Will Bring in a Flurry of New Rules and Regulations Affecting Healthcare,” *Modern Healthcare*, Jan. 2015.

<http://www.modernhealthcare.com/article/20160102/MAGAZINE/301029961>

### Will Year of Mercy Offer New ‘Opening’ On Abortion?

In his September letter outlining reasons for proclaiming a Year of Mercy, Pope Francis “expressed his closeness to post-abortive women, and others who shared responsibility for the direct killing of an unborn child.” He offers “all priests for the jubilee year the discretion to absolve of the sin of abortion those who have procured it and who, with contrite heart, seek forgiveness for it.” This is comforting news to a population that has felt exiled from their faith community. Marianne Luthin, director of the Archdiocese of Boston’s Pro-Life Office and its Project Rachel ministry, reports a surge of calls from women who said “they felt comfortable coming forward because they trusted the Pope. They had been living in the shadows; and now they felt they could receive absolution.” For some U.S. Catholics the announcement brings canonical confusion as local bishops could already grant permission to priests to absolve the sin of abortion. The pope’s pronouncement brings the practice worldwide and signifies his desire to bear witness to God’s great mercy: “The forgiveness of God cannot be denied to one who has repented, especially when that person approaches the sacrament of confession with a sincere heart in order to obtain reconciliation with the Father.” Joan Frawley Desmond, “Will Year of Mercy Offer New ‘Opening’ On Abortion?”, *National Catholic Register*, Dec. 2015.

<https://www.ncregister.com/daily-news/will-year-of-mercy-offer-new-opening-on-abortion/>

### New Guidelines for Heart Transplantation Candidacy Issued

The International Society for Heart and Lung Transplantation has published in *The Journal of Heart and Lung Transplantation* new guidelines to “to help physicians determine which patients may be suitable candidates for heart transplantation.” This updates the previous guidelines created in 2006. Some of the major changes include which diseases will no longer disqualify a potential recipient. The “ISHLT now states that patients with human immunodeficiency virus (HIV), hepatitis, Chagas disease or tuberculosis can now be considered suitable transplant candidates, provided they meet other criteria.”

The new version also addresses a concern in the previous stipulation of the 2006 edition which required heart failure patients to reduce their Body Mass Index down to 35. The new revision requires doctors to ensure “such patients reach a BMI of 30 or less...” Another revision examines the social support of the patient to determine whether they will have the ability to adhere to the necessary outpatient care requirements. Additional changes to the guidelines are contained in the article. Honor Whiteman “New Guidelines for Heart Transplantation Candidacy Issued,” *Medical News Today*, Jan. 8, 2016.

<http://www.medicalnewstoday.com/articles/304757.php>

### Questions and Answers About Obama’s Executive Plan on Guns

According to an AP article by Josh Lederman, the primary approach for President Obama’s executive action regarding guns is to “clarify who is ‘in the business’ of selling firearms and has to get a federal license.” Currently, only licensed dealers are required to perform background checks. Meanwhile, guns sold

by private individuals, at flea markets and gun shows, as well as online are not required to do so. Another part of the action is to increase the number of examiners, hired by the FBI, to process these background checks.

The article addresses questions by potential gun sellers and citizens who are concerned about the effect of the measure. It also explains the legality of such an executive action. The article is timely for health professionals who are concerned about the necessity of gun laws for the protection of public health.

Lederman, Josh. "Questions and Answers About Obama's Executive Plan on Guns," *Associated Press*, January 6, 2016.  
[http://hosted.ap.org/dynamic/stories/U/US\\_OBAMA\\_GUNS\\_QA?SITE=AP&SECTION=HOME&TEMPLATE=DEFAULT](http://hosted.ap.org/dynamic/stories/U/US_OBAMA_GUNS_QA?SITE=AP&SECTION=HOME&TEMPLATE=DEFAULT)

### **A Doctor's Dilemma: How to Treat the Angry Patient**

Sarah Poggi, MD, an obstetrician from Alexandria, Va., wrote a commentary for the *Washington Post* after recently taking an annual online course from her medical system on "workplace violence." She quips about the recommendation to throw coffee at an armed assailant, or a stapler since her floor does not allow food or drink in the hall. Dr. Poggi describes scenarios of patients yelling profanities, assaulting staff members, and forcefully deterring certain medical procedures. However, she, and her fellow staff, did not believe these actions warranted mentioning to the security department of their hospital: "Did I report any of these "behaviors of concern"? No. I justified every case, empathizing with the patient."

What the dilemma comes down to for Dr. Poggi and her fellow staff is the mixed message: "On one hand, we are told to watch for angry behavior and to report

it. On the other, we are incentivized to excuse the same behavior and even accommodate it." With the rise of social media and mass consumer review, doctors and nurses are keenly aware of the effect a negative remark online can have on their career and practice. But, this doctor is tired "of the concept that 'the customer is always right' when a patient displays a 'behavior of concern.'" She desires an honest conversation on the fear such patients bring to a medical facility, and a concerted effort by the administration to put safety above rankings.

Poggi, Sarah. "A Doctor's Dilemma: How to Treat the Angry Patient," *Washington Post*, January 1, 2016.  
[https://www.washingtonpost.com/opinions/a-doctors-dilemma-how-to-treat-the-angry/2016/01/01/01ebdfa6-ae4c-11e5-b711-1998289ffcea\\_story.html?postshare=591451816871290&tid=ss\\_mail](https://www.washingtonpost.com/opinions/a-doctors-dilemma-how-to-treat-the-angry/2016/01/01/01ebdfa6-ae4c-11e5-b711-1998289ffcea_story.html?postshare=591451816871290&tid=ss_mail)

*Students from the Saint Louis University School of Law Center for Health Law Studies contributed the following items to this column. Amy N. Sanders, assistant director, supervised the contributions of health law students Erin E. Grant (J.D./M.H.A. anticipated May 2018) and Abigail Wood (JD anticipated May 2017).*

### **6<sup>th</sup> GOP Debate: What Each Candidate Said About Health Care**

The GOP candidates once again faced off on stage in North Charleston, SC, in preparation for the upcoming Iowa caucuses less than three weeks away. Each of the candidates stressed health care as an important issue they would address. Each proposed different approaches. Donald Trump, calling our health care system a "horror show," expressed that he would repeal the Affordable Care Act (ACA) but ran out of time before sharing how he would "fix" the system. Jeb Bush drew attention to mental health issues, calling for bipartisan solutions to prevent the mentally ill from accessing guns. Senator Marco

Rubio promised to repeal President Obama's executive orders and to get "rid of" Obamacare, calling the ACA a "certified job killer." Senator Ted Cruz proposed repealing a number of taxes enacted under the ACA, an action that would correspond with his proposed flat tax plan. Dr. Ben Carson also suggested a flat tax system that would prohibit people from "taking advantage" of others, as well as a cutback in spending. Governor Chris Christie called for entitlement reforms that would save Social Security and Medicare, while Governor John Kasich promised to freeze all federal regulations for one year, except for health- and safety-related regulations.

Emily Rappleye, *Becker's Hospital Review*, Jan. 15, 2016 <http://www.beckershospitalreview.com/hospital-management-administration/6th-gop-debate-what-each-candidate-said-about-healthcare.html>

### **State Reinforcements Join the Health Insurance Merger Investigations**

After news broke this summer of the possible mergers between Aenta and Humana, as well as Anthem and Cigna Corp, the U.S. Department of Justice immediately commenced an investigation. The House and Senate subcommittees also held investigative hearings to understand the implications of the mergers on the U.S. health care system. Now, at least 15 state attorney generals have decided to join the DOJ in investigating the negative implications of these mergers for health care. Thomas Greaney, co-director of the Center for Health Law Studies at Saint Louis University School of Law, said it was not surprising that state attorneys general would want to join the inquiry since attorney generals can weigh in on local market conditions, which will be important to the Justice Department's ultimate decision on the mergers. Greaney previously served as assistant chief in charge of health care antitrust enforcement at the Justice Department. "They may also have some input into settlement negotiations," Greaney said. Now the

fate of the U.S. health insurance industry awaits reports from both state and federal authorities. Lisa Schencker, *Modern Healthcare*, Jan. 12, 2016 <http://www.modernhealthcare.com/article/20160112/BLOG/160119967>

### **Law on Ultrasounds Reignites Abortion Battle in North Carolina**

In North Carolina, a new state law has sparked outrage in the abortion debate. The law, which has faced staunch opposition, requires that doctors who perform an abortion after the 16th week of pregnancy provide an ultrasound to state officials. This requirement was designed to ensure that doctors complied with existing North Carolina law, which bans abortions after 20 weeks with exceptions only for medical emergencies. Critics of this law argue that its purpose was to intimidate women and physicians and to construct hurdles in access to health care services. The new law, similar to legislation passed in Louisiana and Oklahoma, requires doctors performing abortions after the 16th week of pregnancy to verify the "probable gestational age" of the fetus through an ultrasound that shows the measurements taken of the fetus. These measurements must be sent to the North Carolina Department of Health and Human Services. The law became effective Jan. 1, 2016. Richard Fausset, *The New York Times*, Jan. 10, 2016 [http://www.nytimes.com/2016/01/11/us/law-on-ultrasounds-reignites-abortion-battle-in-north-carolina.html?ref=health&\\_r=0](http://www.nytimes.com/2016/01/11/us/law-on-ultrasounds-reignites-abortion-battle-in-north-carolina.html?ref=health&_r=0)

### **Illinois Non-profit Hospital Tax Exempt Status on Shaky Ground**

On Tuesday Jan. 5, 2016, an Illinois appeals court ruled that part of a 2012 Illinois law that allows hospitals to avoid taxes is unconstitutional. The case was brought to the court by the Mayor of Urbana, Ill., a city of approximately 41,000 people, against Carle Hospital. Mayor Prussing claims that Urbana

has lost 11 percent of its assessed tax value since Carle was relieved of paying \$6.5 million a year in property taxes. In 2012, Illinois hospitals were given relief when state lawmakers passed legislation that simply required a non-profit hospital's charitable services to exceed its property tax liability to qualify for tax exemptions. This new decision invalidates that legislation as being unconstitutional. The questioning of non-profit hospital tax exempt status appears to be a growing trend. In 2015, Morristown New Jersey Medical Center agreed to pay \$26 million to settle a dispute over its tax exempt status. Illinois is not the first nor will it be the last state where non-profit hospital tax exempt status might be questioned. Ayla Ellison, *Becker's Hospital Review*, January 08, 2016 <http://www.beckershospitalreview.com/finance/hospital-tax-exemptions-under-fire-in-illinois.html>

### **Stricter Rules for People Enrolling on HealthCare.gov after Open Enrollment**

Insurers have argued that the rules for special enrollment periods on HealthCare.gov are too broad. Their argument is that people can wait until they are ill to enroll in insurance on HealthCare.gov that, in turn, raises overall premiums and health care spending because these sicker people are costlier. Andy Slavitt, acting administrator of the Centers for Medicare and Medicaid Services, said that some “bad actors” had been taking advantage of the special enrollment period and thus they are responding by tightening some of the requirements for special enrollment periods. He also said that the agency has created an enforcement task force to ensure that people are being honest when applying for special enrollment. However, consumer groups are pressing for additional exceptions that could allow more people to apply for special enrollment. Between Feb. 23 and June 30, 2015 around 950,000 consumers selected a health plan during a special enrollment period on HealthCare.gov. Mr. Slavitt was not specific about

what requirements will be eliminated or changed to ratchet down the special enrollment periods. Stephanie Armour and Louise Radnofsky, *The Wall Street Journal*, Jan. 12, 2016 <http://www.wsj.com/articles/health-law-enrollment-periods-to-be-tightened-1452573856>

### **New Guidelines Support Patients' Access to their Medical Records**

The Obama administration released new guidelines for patient's rights under the Health Insurance Portability and Accountability Act (HIPAA) to access their health information. Jocelyn Samuels, the director of the Office for Civil Rights at the Department of Health and Human Services stated that, “Based on recent studies and our own enforcement experience, far too often individuals face obstacles to accessing their health information.” The guidelines, issued this month, state that doctors and hospitals cannot require patients to state a reason for requesting their records. Health care providers cannot require patients to pick up their records in person if they ask for the records to be sent via mail or email. Health care providers can also not deny a request for medical records because a patient has not paid their medical bills. There are certain exceptions to the rules for psychotherapy notes and health information that might endanger the life or physical safety of a patient or other person. The goal is to enable patients to take an active role in their medical care. Robert Pear, *The New York Times*, Jan. 16, 2016 [http://www.nytimes.com/2016/01/17/us/new-guidelines-nudge-doctors-on-giving-patients-access-to-medical-records.html?ref=health&\\_r=0](http://www.nytimes.com/2016/01/17/us/new-guidelines-nudge-doctors-on-giving-patients-access-to-medical-records.html?ref=health&_r=0)

### **Drug Prices Continue to Rise Despite Criticism**

Drug prices continue to rise. Pfizer Inc., Amgen Inc., Allergan PLC, Horizon Pharma PLC, and others have raised U.S. drug prices for dozens of branded drugs since late Dec. 2015. The increases ranged between 9

percent and 10 percent, according to equity analysts. These increases are on the list prices of the drugs before any discounts or rebates offered by the manufactures. Some pharmaceutical companies such as Pfizer state that they offer considerable discounts off the list prices to patients and depending on income level some patients can receive free medication. However, politicians, health care payers, doctors, and patients have all criticized drug pricing for making medication out of reach for many low-income patients. According to the Centers for Medicare and Medicaid Services, U.S. prescription-drug spending rose 12.2 percent in 2014, accelerating from 2.4 percent growth in 2013. Pharmaceutical companies argue that the rise in drug prices helps to offset the high costs of bringing new drugs to the market. Advocates argue that the U.S. needs a regulatory mechanism to control prices similar to those seen in other countries. Peter Loftus, *The Wall Street Journal*, Jan. 10, 2016, <http://www.wsj.com/articles/drugmakers-raise-prices-despite-criticisms-1452474210>

### **IRS Again Delays Minimum Essential Coverage Reporting Requirement, and Other ACA Developments**

Under the Affordable Care Act (ACA), large employers and providers of minimum essential coverage, such as self-insured employers, insurers, and government programs, must report to the IRS that their beneficiaries have the minimum level of required coverage. The deadline for the first scheduled reports, initially set for early 2015, was delayed by the IRS on Dec. 28, 2015 after the Department of the Treasury concluded that some providers needed additional time to adapt to the new systems and to gather, analyze, and report information. Final forms are now due to the IRS by May 31. Penalties will not be imposed on entities who attempted to comply with the initial deadline but provided incomplete, inaccurate, or no information due to reasonable cause.

This delay may affect some taxpayers, as individuals are not currently eligible for premium tax credits for any month during which they were offered affordable coverage or covered by an employer. However, some accommodations have been made for these individuals; if an individual is deemed eligible for a premium tax credit because employer coverage is unaffordable, but is later determined to have been eligible for employer coverage, the employee will still be treated as eligible for the tax credit. This delay will not affect individuals who have already received tax credits, did not enroll in the market, received employer coverage or coverage outside of the market, or who were otherwise ineligible for tax credits. Individuals who have already received premium tax credits will remain unaffected by the delay. Timothy Jost, *Health Affairs*, Dec. 29 2015 <http://healthaffairs.org/blog/2015/12/29/irs-again-delays-minimum-essential-coverage-reporting-requirement-and-other-aca-developments/>

### **Shedding Some Light on the Problem of Medical Data Loss**

Health care is an industry notorious for its data breaches involving protected health information (PHI), or confidential health information that could be used to identify an individual. However, a recent study by Verizon Enterprise Solutions exposes the true extent of these breaches. According to the study, health care experienced the highest rate of security breaches of all industries studied. The study also indicated that actors within health care organizations were involved in 791, or approximately 43 percent, of these data breaches. The three primary reasons for data breaches were (1) physical theft of items containing secure information, such as laptops, or tampering with devices, (2) lost devices or mistakes such as emailing confidential information to the wrong person, and (3) misuse or abuse of privileged information by actors such as employees.

Unfortunately, data showed these breaches often took months or even years to detect. One method proposed to counteract this data breach has been more sophisticated tracking of individuals that would allow auditors to monitor employees' computer activity. Because this sensitive medical data often presents a vital key to timely diagnosis and treatment of disease, improvements in protecting this information remain imperative.

Heather Landi, *Healthcare Informatics*, Dec. 16, 2015  
<http://www.healthcare-informatics.com/article/shedding-some-light-problem-medical-data-loss>

### **Why Are Many CO-OPs Failing? How New Nonprofit Health Plans Have Responded to Market Competitions**

Along with its sweeping reforms designed to improve health care access, the Affordable Care Act (ACA) created the Consumer Operated and Oriented Plan (CO-OP) Program to allow customers to choose a nonprofit insurance option with strong customer focus. However, this program has experienced overwhelming failure; half of the 23 CO-OPs have shut down or will soon shut down, and all but two have failed to meet their expected enrollment or profitability. A new report by The Commonwealth Fund discloses some of the reasons behind these failures. First, to meet certain deadlines, CO-OPs were forced to outsource certain processes, limiting the CO-OPs' ability to control costs and manage the quality of these services. Second, a prohibition on use of federal funds for marketing placed some hindrances on CO-OPs' profitability. Additionally, several CO-OPs originally offered platinum plans; however, the lower out-of-pocket cost of these plans tended to attract consumers with significant health needs. The higher costs incurred eventually lead all CO-OPs to drop these plans. Another difficulty experienced by CO-OPs was the lack of historical data normally used

to estimate costs. Combined with unpredictable enrollment numbers, more than half of the CO-OPs did not have enough enrollees to cover expenses. Furthermore, though the ACA promised financial aid to help stabilize the smaller CO-OPs, this aid was much lower than anticipated and insurers had to wait more than twenty-one months for payment.

Though eleven CO-OPs remain, it is likely they will continue to face challenges to their sustainability. Some of these challenges stem from the nature of the health care industry; others result from political decisions. The failures of these CO-OPs merely highlight the difficult but necessary challenges faced in providing competitive choices in health care coverage, as well as the future investments required if the CO-OPs are to survive. Sabrina Corlette, Sean Miskell, and Justin Giovannelli, *The Commonwealth Fund*, Dec. 10, 2015

<http://www.commonwealthfund.org/publications/fund-reports/2015/dec/why-are-co-ops-failing>

## Geriatric Dialysis: Understanding of Effectiveness and Appropriateness Continues to Evolve

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*Editor's Note – This article is a review of the articles listed below regarding geriatric dialysis with the assistance of Lori-Ashmore Ruppel, CHA mission program and research associate.*

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- Bebem, Tomasz and Dena E. Rifkin. “The Elderly are Different: Initiating Dialysis in Frail Geriatric Patients.” 28, no. 3 (May-June 2015)
- Farragher, Janine and Sarbjit Vanita Jassal. “Rehabilitation of the Geriatric Dialysis Patient.” *Seminars in Dialysis* 25, no. 6 (November-December 2012)
- Dannelke, Lenora. “Dialysis: A Forever Decision.” *Aging Well* (Winter 2011).
- Polinder-Bos, H.A. and others. “High Fall Incidence and Fracture Rate in Elderly Dialysis Patients.” *The Netherlands Journal of Medicine* 72, no. 10 (December 2014)
- “Clinical Practice Guidelines on Shared Decision-Making in the Appropriate Initiation and Withdrawal from Dialysis,” Renal Physicians’ Association (2010)
- Ross, William, M.D. “God Panels and the History of Hemodialysis in America: A Cautionary Tale.” *Virtual Mentor, AMA Journal of Ethics* 14, no. 11 (Nov 2012):: 890-896.
- Shum, Chen Keung. “Outcomes in Older Adults with Stage 5 Chronic Kidney Disease: Comparison of Peritoneal Dialysis and Conservative Management.” *Journals of Gerontology: Medical Sciences* 69, no. 3 (March 2014)
- Shandna, Shultz, et al., “Is There a Rationale For Rationing Chronic Dialysis?” *BMJ* 1999 (318:7178): 217-23.
- Singh, Pooja and others. “The Elderly Patient on Dialysis: Geriatric Considerations.” *Nephrology Dialysis Transplantation* 29 (2014)
- Tamura, Kurella, et al., “Functional Status of Elderly Adults Before and After Initiation of Dialysis.” *NEJM* 361 (2009): 1539-47.
- Treit, Kathryn and others. “Timing of Dialysis Initiation in the Geriatric Population: Toward a Patient-centered Approach.” *Seminars in Dialysis* 26, no. 6 (November-December 2013)
- Van Loo, I.N. and others. “A National Survey on the Decision-making Process of Dialysis Initiation in Elderly Patients.” *The Netherlands Journal of Medicine* 73, no. 5 (June 2015)



## Introduction

The use of dialysis on a broad basis began in 1962 when the Artificial Kidney Center in Seattle developed an allocation system for dialysis based on “social worth.” This was quickly abandoned, and Congressional action in 1972 (ESRD) made dialysis available to virtually anyone under 75 who was eligible for Social Security. This was clearly a moment of naïveté. No one imagined that the 10,000 patients receiving dialysis when it started would expand to the 320,000 who receive it today at an annual cost of \$39.5 billion or 8 percent of Medicare costs. It has, in the words of one nephrologist, become “an unsustainable behemoth.” What’s more, the fastest growing number of new patients are over 75. Dialysis is just one case study of the effect that growing longevity will have on health care costs in the future.

There have also been questions about the effectiveness of ESRD for geriatric patients, about criteria for decision-making, and about the proper moral agency. Who makes the decision to begin or terminate dialysis, and on what basis? Do poor outcomes and high cost justify initiation of dialysis for the frail elderly, especially when “conservative management” may work just as well? These questions, as well as the relationship of ESRD to the emerging field of palliative care, are the core of the several articles cited above.

## Criteria for Decision Making

Initially, not that many people qualified for dialysis, especially those over a certain age. Gradually, the age restriction was dropped. Today most nephrologists agree that it is not the absolute age that matters, but other factors such as co-morbidities, dementia, falls and fractures -- conditions that occur more frequently among the elderly. In addition, research seems to indicate that the benefit of dialysis for patients over 85 is limited (Romano et al, 2014, 235). “There have

been changes in the attitudes of nephrologists,” says Dr. Michael Germain. “Recent studies have shown the very, very poor outcomes for patients with renal failure once they’ve gotten into long-term care” (Yard). Another says that there is a “growing realization that dialysis does not suit all patients (Mutha, 2717); yet another says that dialysis “does not confer a statistically significant survival advantage of non-aggressive, conservative renal care” (Ross 892), and that in many cases conservative management of kidney disease is just as effective as dialysis (Shum et al., p. 308). They also note that conservative management is not simply “no dialysis.” Rather, “it shifts the focus from efforts to prolong life to those that focus on symptom control, quality of life and care support by a multidisciplinary team (Shum, 313). Shandna and Shulz note that predicting survival on dialysis depended more on the level of co-morbidity and functional isolation than on the age of the patient.”

Very recently, one researcher said that “little is known” about what nephrologists consider when they face a decision about initiating dialysis for elderly patients. There is evidence that patient preference, co-morbidities, dementia and poor physical functioning were taken into account. But it is not clear whether “mood disturbances, ADL impairment, frailty and cognitive impairment figured in (vanLoon et al., 228). One French study suggested that psychological and physical deteriorating were principle factors in decisions to refuse or discontinue treatment, but that the decision is deemed legitimate only if dialysis results in a major loss of autonomy or isolation from the family or society.”

There have been several attempts to establish better criteria and a better process for assessing an elderly patient’s suitability for dialysis. A number of authors referred to “Guidelines to Assist Decision Making” taken from the American Society of Nephrology and the United States Renal Physicians. These guidelines

list shared decision making, informed consent, estimating prognosis, conflict resolution, advance directives, withholding or withdrawing dialysis, special patient groups, time-limited trials, and palliative care. (Full text of their guidelines can be found at [www.aacn.org](http://www.aacn.org)). A “Recommended Approach to Starting and Discontinuing Dialysis in the Elderly” is found in Thorsteinsdottir et al. (2097).

### Who Decides?

We’ve come a long way from the days when decisions about dialysis were made by a panel, who based their decisions on social value! All researchers placed high priority on patient autonomy, or at least participation, but few felt that was adequate. Most suggested some form of “shared decision making,” that took into account clinical and social factors as well as patient preference. One study noted that in France patients’ refusal to continue treatment is not taken into account. The physician seeks the patient’s opinion, but makes the final decision (Clement et al., 2450). A U.S. nephrologist said that about half of his colleagues decide whether to even raise the issue of initiating dialysis, opting instead to make a unilateral decision that it is not appropriate.

Muthalagappan et al. distinguish among the “fully autonomous” model, which risks overwhelming individuals; a paternalistic model, and a “shared decision-making model.” They note that “difficulties in predicting” prognosis sometimes leave patients with a sense of uncertainty that hinders their involvement. In the end, they say, “the best choice is defined by what matters most to patients, especially when outcomes are variable.” (2720).

Still, “it is hard to identify clear decision points for patients and their families,” says Dannelke. She cites one physician who said, “Older folks in the predialysis clinic would say very routinely, ‘Nope, not for me. Never.’ ...And the next time I saw those folks it

would be in the maintenance unit and they’d be on dialysis...How did that happen?” (26).

Thorsteinsdottir and colleagues note that even if shared decision making is desirable, “nephrologists report that they feel ill-prepared to have” the discussions necessary for such decision-making, that patients often do not feel they have adequate information; that physicians bring their own biases, and families tend to be overly optimistic. They also note the danger of falling into a binary approach, where it is either “dialysis or nothing.” Sekarrie et al note the disadvantage of late referral, and say that primary physicians need more education about referral, and that nephrologists need more education about ethics and the law of discontinuing dialysis and about planning for advance directives (470).

### Conservative Management and Palliative Care

A number of authors mention palliative care; three address it at some length. Yard notes that palliative care is an option that is the result of refocusing from increasing survival to enhancing quality of life. Romano, writing from Brazil, promotes a shared decision-making model, but says that foregoing dialysis is only possible in places where there is “a good palliative care program,” to provide other care. Brennan discusses holistic palliative care; he is the only author to take explicit account of the spiritual and religious needs of patients, an important aspect of care in Catholic hospitals.

### Dialysis, Economics and Justice

Several writers note the economic aspect of dialysis. William Ross says clearly that it is time for the government to decide whether it is time to phase out the subsidization of care to all patients with ESRD and let patients under 65 seek coverage from third party payers. This would have a dramatic economic impact. Thorsteinsdottir and colleagues note that in the U.S., dialysis is the only specific medical

treatment that gets universal coverage. He maintains this is “discrimination by diagnosis.”

Ross suggests that we should look to the “quality-adjusted life-year” (QALY), the number of years of improved quality of life patients stand to gain from dialysis, as one way to bring the benefits vs. economic burdens calculation into focus. He also says that while he sees Congressional action as unlikely, he thinks it may be time to consider phasing out subsidization of care for all patients on ESRD and let patients under 65 seek coverage from third party payers (893).

Several things are clear from this brief literature review. First, the unique payment arrangement for dialysis has probably contributed to over-use. Second, dialysis is not the best option for all patients, especially those who are elderly and have multiple comorbidities. Third, even if shared decision making is the ideal, patients need more information, and physicians need better ways to lead discussions of options. Fourth, dialysis should not retain its privileged place in funding; other health care needs are equally important. Finally, the time seems right to merge decisions about dialysis with the rapidly growing discipline of palliative care so that it becomes part of an overall strategy for the patient’s good.

# Health Care Ethics USA

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